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'People are creating policy up there, they are not coming down': nurses' views on the expansion of routine provider-initiated HIV testing and counselling in Nairobi, Kenya.

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'People are creating policy up there, they are not coming down'

Nurses' views on the expansion of routine provider-initiated HIV testing and counselling in Nairobi, Kenya

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Introduction

In this report, we present selected findings from an exploratory piece of qualitative research on HIV testing that was undertaken in 2007–2008 with nurses in Nairobi, Kenya. At the same time, we share our own story of how this research came about and how NHIVNA research funding was able to lay the foundations for a larger study that will hopefully give voice to patients and HIV nurses in Nairobi and will develop HIV nursing research capacity in the country.

Developing a research collaboration

In 2006, Eunice Ndirangu, a BSc-qualified nurse from Kenya won a prestigious scholarship to fund an MSc in the UK. Eunice came to the University of Nottingham and completed her MSc in Advanced Nursing Practice – a programme that Catrin Evans is involved in. When Eunice returned to Kenya, she was quickly offered a job as a lecturer with the Aga Khan University in Nairobi, working on their Advanced Nursing Studies programme. A common problem for nurse-lecturers in Kenya (as in the UK) is that they are heavily drawn into teaching responsibilities and find little time or support for research. In a context of severe human resource shortages, teaching is clearly vital, but there is also a critical need to develop an evidence base for nursing that is context-specific and that addresses questions of relevance to local nursing practice. Catrin and Eunice decided to undertake some research together (funded by a NHIVNA/Boehringer Ingelheim Research Grant), exploring the implications for nurses of the recently announced World Health Organization (WHO) (and national) guidelines promoting the widespread expansion of routine provider-initiated opt-out HIV testing in Kenya [1–3].

Background to routine provider-initiated HIV testing and counselling

In a previous paper, we have described the rationale for, and potential challenges of, routine provider-initiated HIV testing and counselling (PITC) in sub-Saharan Africa [4]. In this region, 89% of the population has not been tested for HIV. Routine testing aims to increase the numbers of people diagnosed early, minimise morbidity and mortality from AIDS by enabling timely treatment and care, and prevent onward transmission through intensive post-test counselling. The public health rationale for expanded HIV testing seems clear. However, a number of concerns have been raised, focusing primarily on challenges foreseen in the implementation process set within the contexts of human and health service resource shortages and severe social stigma [5]. Key concerns focus on whether/how informed consent, privacy and confidentiality will be upheld in overstretched healthcare settings, and whether appropriate post-test counselling, treatment and support will be provided to all those who need it. Quantitative research demonstrates that routine testing is effective in increasing testing uptake, however qualitative evidence on the implementation process is lacking [6].

In Kenya, nurses are the main providers of HIV-related services and much of the burden of changed HIV testing practice has fallen upon their shoulders. Two studies from Southern Africa indicate that nurses find HIV testing a stressful and difficult job owing to the challenge of supporting patients through an emotionally charged time and feeling unsupported in their work environments [7,8]. Similar research has not yet been carried out in Kenya. Support for nurses is critical in ensuring that expanded HIV testing is carried out in a patient-centred manner.

Research aims and methods

This research set out to explore two questions:

- What are nurses' views on routine provider-initiated HIV testing and counselling (PITC)?
- From a nursing perspective, what are the challenges and facilitators of good practice in implementing routine HIV testing and counselling?

The research aimed to explore nurses' views and experiences of HIV testing from their own perspectives. For this reason, it adopted a qualitative approach [9]. Ethical permission was obtained from the Aga Khan University Research Ethics Committee, the Kenyan Ministry of

Education, Science and Technology and individual hospital ethics committees. The research comprised two focus group discussions and 15 semi-structured interviews with nurses working in government health facilities in and around Nairobi (where routine testing has been in use since 2005). Written, informed consent was obtained from all research participants. The focus group discussions explored general views and attitudes to routine HIV testing whereas the interviews explored nurses' own personal experiences [10]. Of the interviewees, 10 worked on in-patient wards (medical or TB wards), four worked in health centres (of which one was an HIV comprehensive care centre) and one worked as a research nurse on an HIV treatment project. Amongst the focus group participants (n=12), 10 worked on in-patient wards (mainly medical wards) and two worked in health centres (of which one was an HIV comprehensive care centre). The sample was specifically selected in order to reflect a range of different hospitals and health centres. Nurses from nine different hospitals, three health centres and one non-governmental organisation were represented. The sampling strategy means that the findings give a general (and hopefully fairly representative) view from a range of workplaces. The disadvantage of this is that it is becomes more difficult to link the findings (and subsequent recommendations) to specific workplace situations or policies. The data were analysed thematically and the key themes were agreed by Catrin and Eunice [11].

In this article, we focus on just one initial theme from the findings: 'nurses' views and attitudes towards routine HIV testing'. Other themes focus on the implementation of routine testing, specifically; 'pre-test process and informed consent', 'post-test support and confidentiality', 'counselling challenges', and 'organisational support' and will be presented in subsequent papers.

Nurses' views and attitudes to routine provider-initiated HIV testing and counselling

Current obstacles to testing

Nurses felt that current low rates of HIV testing were strongly associated with denial (or lack of personalised risk perception), a lack of knowledge or understanding about the availability and accessibility of HIV treatment, and with social stigma. In spite of the fact that treatment and care has become more widely available throughout Nairobi, past experience means that many people still view HIV as a death sentence. In addition, although treatment is theoretically free, it incurs many other costs such as those associated with transport to attend clinic appointments, getting an adequate diet or obtaining associated medical tests. Together, these factors create significant psychological and material barriers to HIV testing:

> *It's not very easy you see. People fear the outcome, because maybe stigma, and still, why should I know about this disease when there is no treatment? Let me stay with it. I die like everybody else who is suffering from any other disease (P5:16).*

An unwillingness or inability to contemplate the potential impact of an HIV diagnosis on a long-standing relationship was cited as another potential barrier to HIV testing. This was particularly the case for women:

> *So the uncertainties is contributing a lot to people fearing to be tested, especially the married people because they are not sure ... as the day goes by you don't know where your partner is, so you just live by the grace of God that by the end of the day that HIV doesn't come into the house ... we keep on living with that fear (FGD2:3).*

Nurses also noted that men in particular were more reluctant to come for testing (and to seek healthcare in general), and felt that a lack of male counsellors may also be a barrier:

> *It is to do with health seeking behaviour. You won't see a man going to hospital because he has a cold ... so they are not feeling sick and you are telling them to be tested. Also the issue of genfer, you find that the hospitals are women dominated – rarely will I go to find a man counsellor (FGD2:7).*

The social stigma surrounding HIV was cited as the most significant obstacle to HIV testing. Nurses noted that people are very reluctant to have a test in a clinic in their own locality due to fears over confidentiality. The perceived negative reaction of relatives or partners is another obstacle. The focus group discussions generated a great deal of debate about how nurses themselves contributed to stigma and fear. They noted their own reluctance to get tested and to discuss HIV openly within their communities:

> *As staff, we need to change our own attitudes towards the testing. I remember there was a time we were just in a session for PITC and I was asking how many of us can go to the VCT we have in the hospital to be tested, and nobody raised their hand. So the question is, if I cannot access the VCT, how do I expect somebody who is a stranger to access it? It shows I have no confidence in the system ... if I cannot believe in it, how can I sell the same policy to somebody else? If I have never been tested, I don't know how it feels to wait anxiously for a result to come through? For us to move, we have to open up. Let us talk not from a point of ignorance but of knowledge. 'I know my status and this is why I'm attending to you and I can declare it if called upon' (FGD2:2).*

In addition, there was an open recognition amongst nurses that, at times, an organisational/professional culture of gossip and judgementalism (directed towards other nurses as well as patients) was contributing to HIV-related stigma and fear of testing:

> *I also think that the attitude of the health worker ... we have not really improved so much, I think we are also discussing these patients despite saying that we are going to keep the confidentiality. I think it has killed the morale of the community (FGD2:1).*

As noted in the quotes above, nurses felt that a first step in addressing these obstacles was for nurses themselves to be supported to face their own HIV risk and to create a professional culture that would support HIV-positive nurses, and uphold confidentiality:

> *Let it start with us, first we have to kill the stigma within ourselves and within our colleagues...we should just kill that so that we can implement PITC (P15:15).*

Potential benefits for routine testing

On the whole, the study participants supported PITC and identified many potential advantages to routine HIV testing. These included the following.

- Reducing stigma:

  > *I think stigma is reduced, because most patients you see, they get diagnosed and they go back into the community and have seen the importance of testing and treatment. So you find one patient will bring another – and says – 'if it was not because of this hospital set up and the testing I would have been dead by now' (P4:17).*

- Normalising HIV and reducing the amount of pre-test counselling that is required:

  > *I think pre-test counselling is a way of stigmatising HIV/AIDS. It is stigmatising the disease because we are treating it as a special case. It is a special disease, you must be protected, you have to do this and this counselling for you to give consent. Consent for what? You would have cancer, it would also kill you and hypertension its going to kill you. If we make it one among many that stigma will come down (FGD2:2).*

- Taking the pressure off the patient. The provider-initiated approach could encourage some patients to discuss their HIV concerns when they may previously have hesitated to speak out:

  > *I think it is a good idea. Before that, a patient would come inside his heart wanting to do the test but just asking would be a problem, so when you come forward and tell them, most of them accept (FGD1:1).*

- Prevention of unnecessary illness and death
- Enhancing prevention efforts
- Reducing waiting times due to use of rapid tests

However, in many interviews, nurses stressed that PITC implementation and acceptance required concurrent community awareness-raising events to tackle stigma and a reliable supply of testing kits and antiretroviral treatment to avoid disappointment and disillusionment amongst patients:

> *Sometimes you do the test, you may not have the drugs...you don't have the nevirapine, you don't have the AZT, you may not even have the septrin to start the babies on – so you find that even now you know their HIV status, so what? It ends there (FGD2:4).*

In addition, some nurses reiterated that follow-up care of those with HIV also needed to become more 'normalised' and less segregated, to reduce stigma and to enhance confidentiality:

> *There are certain cubicles, like if the relatives come and now they know that if you are in that cubicle, you are HIV positive, so even if you tell them all the information, relatives won't want to be tested for HIV because they don't want to be associated with that cubicle...in my place if you are seen going to that pharmacy for HIV drugs then you are scared because of the stigma, so most of them opt not to take the drugs (FGD1:2).*

Potential benefits for routine testing

Although there was broad support for PITC, many nurses also expressed reservations and were particularly aware of the potential for PITC to breach human rights. The main concerns were as follows.

- People may be deterred from seeking care if they know it will involve an HIV test:

  > *Many people would run away from hospitals. They will seek healthcare from other places. Back doors, pharmacies and wrong places (P6:15).*

- Patients may feel pressurised or coerced into having a test:

  > *The patient will look at you like you are the superior and just opt for the test even when they were not really psychologically prepared (FGD1:2).*

- PITC may affect the trust between patient and professional:

  > *Some patients will wonder, why is she telling me to go for an HIV test, what does she think of me? They might think you are judging them when you are not (FGD1:5).*

- Patients need to be able to make an informed decision:

  > *People should be given health education so that you can know the advantages and disadvantages of being tested so they can make an informed decision. You are not forced (P5:17).*

- Fears that confidentiality is easily breached, especially in overcrowded ward environments:

  Sometimes in our set ups we have patients who have to share beds and the next patient sees the result so I feel at that point we've lost it (FGD1:2).

  ... In a maternity setting, it is the office that you receive reports, that doubles as a counselling room, that doubles as a discharge room. You know it is everything so it becomes very difficult to say that you can assure privacy and confidentiality (FGD2:3).

- Concern that condensing pre-test counselling fails to adequately prepare patients for a positive result:

  In 10 minutes the thing is done...and when they end up positive, you find most of them are not able to cope (FGD1:3).

Nurses noted some resistance amongst staff and also community members when PITC was first introduced in their clinical settings, but most felt that the fears about driving people away from treatment had ultimately been unfounded. None the less, one anecdote reveals that PITC implementation needs careful management:

Yah, when we started the PITC programme, word went around the community that when you go there you are forced to be tested. Though you are not really forced but if it is suggested at every entry point, the people look at it as coercion...so we experienced a decline in the numbers of clients that we were receiving, especially the children (FGD2:4).

In sum, nurses gave PITC a cautious welcome, but their own experiences gave rise to considerable caution about the nature of its implementation.

Nursing roles and HIV policy implementation

A very strong theme that emerged from the findings (particularly from the focus group discussions) was the way in which nurses felt disempowered, characterising themselves as the objects rather than the agents of HIV policy-making:

If you look at all the programme implementation, anything on HIV, it ends up with the nurse. If the nurse does not implement, then the whole programme falls back. But if you look at who is being rewarded for that particular programme, the nurse is at the back, so you see there is a lot of de-motivation and if a new programme comes it is received with a lot of negativity because it is an increase in their work load. Somebody is going to be funded for that programme, they are going to have their papers well done because of that programme, yet it is the effort and the sweat of a certain nurse who did the hard work, yet they are not recognised (FGD2: 6).

Thus, on one hand, PITC was welcomed for its potential to tackle HIV transmission and care, but on the other, it was seen as yet another example where nurses felt that their own role in policy/service development and implementation was being overlooked:

I would say that so long as our state policy shall continue to be formulated in ivory towers, and the nurses and the patients, the consumers, are never involved – we shall continue to suffer. So long as people come there and they sit in Grand Regency, sit in Intercontinental and they say, now, let us introduce a new program ... but we are not going to be down there to see this nurse who has seventy patients. People are creating policy up there, they are not coming down (FG1:4).

Nurses complained strongly about a lack of recognition of their expertise and of their hard work, and complained that sponsored programmes were creating a target-driven culture:

Like when you have the donors who maybe funded the training, they also want their numbers to justify the money for the training. So you find that they are pressurizing the staff such that you are no longer interested in the patient welfare and this has been really a complaint from many health workers. Such that you are given numbers – if you do not test this many numbers then you are a failure...and the providers are wondering where this 50 will come from, if we coerce these patients to be tested then we are going to sound a scaring alarm to most of them who are coming around and they won't even come. And then it won't be provider-initiated, it will be provider-coercion (FGD2:5).

A target-driven approach to PITC seemed to be operating in a number of different health facilities. The strict monitoring of testing targets within a hierarchical organisational structure led to nurses feeling pressured to emphasise quantity over quality and to spend precious time on administration:

Okay one of the challenges we as nurses we also face in terms of HIV is that we are judged by the number of clients we see but not with the quality of work ... because if you see all those mothers at the PMTCT they will be very happy when they come for the supervisory visit but they will not bother to find out the quality of work you did with each client ... And then – reporting – you come at the end of the month and you find that the whole table is full of papers, books – if you miss to fill one copy like this, somebody comes on your neck the next day and says that you are late for this or that report – what – so you find the nurse is overwhelmed and the nurse is doing

> *the work of the clinician, the doctor, the clerk, and even a counsellor ... You have been saying that the nurse is the backbone but it is coming to a time when the backbone is breaking so someone needs to recognise that (FGD2:3).*

As the above quote illustrates, some nurses expressed a sense of burnout, overwhelmed with the quantity and complexity of the work they were being expected to do. This attitude was in marked contrast to that of the few interviewees who were lucky enough to work in supportive environments where they had been encouraged to develop autonomous roles:

> *It was a new role for nursing, which when I look at critically had also been the missing link in assisting our patents to understand HIV/AIDS at an early stage. Other nurses felt it was an added burden to them and were afraid of giving the wrong results. But I felt that at least as a nurse, I had ownership of HIV patients because my opinions on management and treatment were highly regarded (P1:1).*

The above example was unusual, however. Nurses commented that there was little incentive to take on additional roles when these were not recognised, and noted that they also faced resistance from doctors or clinical officers in taking on additional diagnostic responsibilities:

> *Even when it comes to doing PITC, if you are trained and the other nurse counsellor is not there, you are not much willing to do it – there is no recognition for it, there are no funds, so you just wait until she comes back (P2:5) ... The doctors feel you are undermining them – there is so much you know, but you are not allowed to practise (P5:9).*

In sum, nurses' attitudes to PITC were strongly coloured by the nature of their working environments and those in which they felt they had little control, or where they received little recognition had a negative impact on staff motivation and quality of care.

Conclusion and reflections

These findings support the call for caution in rolling out PITC [12,13]. The Nairobi nurses have identified a similar range of potential advantages and disadvantages as other commentators [5,14]. Their views concur with the 2007 WHO guidelines [3], which stress that PITC should only be implemented alongside efforts to create an 'enabling environment' including community awareness-raising and provision of adequate treatment and follow-up services. The 2007 WHO guidelines [3] also stress the need for staff training. Interestingly, these guidelines refer to staff as 'health workers' (recognising that different cadres and even lay people perform HIV testing in different contexts). Use of the generic term 'health workers', however, fails to make explicit the reality that in many countries (as in Kenya) it is primarily nurses who conduct HIV testing, and that the introduction of new testing policies needs to be considered alongside wider professional debates on the development, expansion and recognition of nurses' roles within the wider workforce structure. This study clearly demonstrates that the addition of more and more 'tasks' to nurses' job descriptions without a concurrent attempt to develop professional recognition and autonomy (as well as mechanisms for nurses to participate in policy-making) inevitably leads to dissatisfaction, de-motivation and a task- and target-oriented approach to patient care [16–18].

The findings of this study have been disseminated to selected study participants, nursing leaders, educators and practitioners at two international conferences in East Africa. A further paper (in progress) will outline the complexities of HIV testing from a nursing perspective. However, we have both felt that interviewing nurses about their practice provides only a partial picture of the complexities of delivering HIV care. Moreover, in all of the debates on PITC in sub-Saharan Africa, the patient voice has been singularly absent. For this reason, we are continuing our research collaboration and Eunice has now embarked on a PhD in Nursing at Nottingham University where she will work closely with an established HIV service provider in Kenya to observe everyday practice in PITC and to interview patients about their experiences of the testing process and subsequent follow-up care. The findings from the in-depth follow-up study will hopefully produce recommendations for practice development and material that can be used in PITC training.

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